Stalking a Furtive Killer:
A Review of the Federal Government's Efforts to Combat Hepatitis C
Testimony of Ann Jesse for the National Hepatitis C Advocacy Council
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I. INTRODUCTION

My name is Ann Jesse. I am a founding member of the National Hepatitis C Advocacy Council, a national coalition of hepatitis C advocacy organizations and the founding Executive Director of Hep C Connection, a national nonprofit network and support system for people living with hepatitis C. I thank you, Mr. Chairman, for the opportunity to address this grave public health threat.

Former Surgeon General Dr. C. Everett Koop described the hepatitis C epidemic as, "one of the most significant preventable and treatable public health problems facing our nation…. a graver threat than the AIDS crisis."[1] The hepatitis C epidemic is often called "the silent epidemic" because despite the ominous warnings of experts like Dr. Koop and his successor Dr. David Satcher, the general public and many people in the health care and public health communities still remain uninformed about the threat posed by the current hepatitis C crisis.

Dr. Miriam Alter of the Centers for Disease Control and Prevention warned us in 1991 that hepatitis C was "a sleeping giant."[2] Others soon realized the far-reaching personal and societal threats posed by the sleeping giant. But the warnings were not acted upon with sufficient rigor to contain a problem of such magnitude. So today, we are faced with an awakened giant, a public health crisis that is growing day by day. The crisis will continue to grow in destructive capacity for the foreseeable future, until we meet this foe with sufficient funds and rigor to control it. Those of us in this room today have an urgent and crucial responsibility to change the course of this crisis.

II. WHY BE CONCERNED ABOUT HEPATITIS C?

As you have heard, approximately 4-5 million Americans are currently infected with the hepatitis C virus, and an estimated 30-35,000 new infections occur each year. Hepatitis C is an insidious and often silent disease for many years. The early quiescent nature of chronic hepatitis C is one of the most fundamental reasons it poses such a perilous public health threat. The vast majority of people currently infected with the hepatitis C virus are unaware they are infected. Without proactive screening, many of the millions infected will not be diagnosed until they develop serious complications. And in the interim, these millions of infected Americans run the risk of unwittingly infecting countless others with this potentially life-threatening virus.

Chronic hepatitis C ultimately leads to cirrhosis in 20-30% of those infected with 10% progressing to liver-failure or liver cancer for which liver transplantation is the only proven lifesaving measure available. Over the past decade, the incidence of liver cancer has increased greatly, as has the number of people in need of liver transplantation. Most experts attribute these alarming trends to the current hepatitis C crisis.

Based on incidence and prevalence data, and our current knowledge about the clinical course of hepatitis C, we can expect that of the 5 million people currently infected, at least:

- **1, 250,000 will develop cirrhosis**
- **125,000 will require liver transplantation for liver failure and/or liver cancer**

To give you some frame of reference to comprehend the magnitude of these figures, think of the number of people in a city the size of New Orleans, LA or San Antonio, TX or Indianapolis, IN or San Diego, CA. Now try to imagine that every man, woman, and child in the city is suffering from hepatitis C-related cirrhosis of the liver. That is what this treacherous giant called hepatitis C has in store for us – unless we act immediately to intervene in this public health crisis.

Another way to comprehend the magnitude of the problem is to consider how the number of people infected with hepatitis C compares to other well-publicized health problems with which we are all familiar (see Figure 1).[3, 4, 5, 6, 7] HIV is notably absent from this graphic. The reason is that because of the way HIV/AIDS is reported, it is currently not possible to determine how many new infections occur each year. However, according to CDC, an estimated 570,000[8] people in the US were living with HIV/AIDS in 2003, compared to an estimated 3-5 million people living with chronic hepatitis C.

III. TAKING CONTROL OF THE HEPATITIS C CRISIS

A. Integration into Pre-Existing Programs Alone is Inadequate

The National Hepatitis C Advocacy Council appreciates the fact that there are several individuals in the Department of Health and Human Services who understand the magnitude of the hepatitis C crisis and are willing to dedicate the efforts needed to intervene effectively. However, those of us who understand the urgency of this crisis have been stymied because the response at the federal level to this crisis has been starkly insufficient to deal with the magnitude of the problem. Specific and well-defined steps are necessary to bring the hepatitis C epidemic under control.

An effective disease control and prevention program must be tailored to fit the specific characteristics of the disease being targeted. In other words, effective programs are <u>disease-specific</u> and take into account the characteristics of the disease such as: how it is transmitted, the natural course of the disease, the population at risk, and available treatment options. Herein is a foundational problem with the current DHHS plan which attempts to address the hepatitis C crisis **solely** by integrating hepatitis C prevention and control into pre-existing HIV/AIDS and sexually transmitted diseases (STDs) programs. Although HCV and HIV have some shared routes of transmission, they are distinctly different viruses and diseases. The risk groups and relative risks of acquiring these two very different viruses from certain activities are simply <u>not</u> the same.[9, 10, 11, 12, 13, 14] An integration only approach is doomed to failure.

Should HCV prevention and control efforts be integrated into existing HIV/AIDS and STD programs? Of course! But HCV prevention and control efforts must go far beyond integration if we hope to bring this crisis under control. The response to the current HCV epidemic must be similar in scope and magnitude to the threat it poses. Trying to address the HCV crisis with the current plan and funding is akin to trying to stop a hemorrhaging artery with a band-aid. It simply will not work. A significantly more substantial response is urgently needed.

B. The Potential Costs of an Inadequate Response

The hepatitis C crisis grows more serious each day. A landmark study published by Dr. John Wong in the *American Journal of Public Health*[15] laid forth the dire consequences of the currently unchecked hepatitis C crisis. He predicted several devastating personal, societal, and fiscal developments (see Figure 2). The accuracy of Dr. Wong's predictions are already declaring themselves in the rising rates of chronic liver disease, increased incidence of liver cancer, and increasing demand for liver transplantation. But we are only at the beginning of this devastating course; it will grow far worse unless we take immediate action to change the current course of the hepatitis C crisis.

The good news is that we have not yet squandered our opportunity to change the ultimate outcome of this public health crisis. In the past decade, great advances have been made in the treatment of hepatitis C, and with appropriate therapy, nearly 50% of those treated for their disease are able to successfully clear the virus and halt further disease progression. In other words, we are at a crucial juncture in this crisis. If we act <u>now</u> and successfully identify and treat those at greatest risk for the development of liver failure and/or liver cancer, we can save lives, salvage productivity, and ultimately decrease the burden of this disease.

From a fiscal standpoint, immediate intervention in the hepatitis C crisis is a matter of simple arithmetic. Funding for hepatitis C education, counseling, testing and treatment will be offset by future savings through the prevention of liver complications such as chronic liver disease, liver failure, liver cancer, and liver transplantation.

Unlike HIV, which requires life-long antiviral therapy, the treatment for HCV is limited. A successful course of therapy is completed in 24-48 weeks. For those who clear virus, no additional antiviral therapy is required. For all intents and purposes, these patients have been cured of chronic hepatitis C. The bottom line is that identifying and treating hepatitis C is clearly cost effective (see Figure 3).

C. Establishing an Effective Hepatitis C Prevention and Control Program

While integration of hepatitis C prevention and control activities into existing HIV/AIDS and STDS programs can only be seen as a partial response to the hepatitis C crisis, these programs *do* provide a good working model for what an effective hepatitis C prevention and control program should look like (see Figure 4).

The focus of CDC's current **National Hepatitis C Prevention Strategy** is integration into existing HIV/AIDS and STD programs. We believe this approach was taken because lack of funding prevented virtually any other approach. Clearly, CDC is well-aware of what is needed for effective control and prevention as evidenced by numerous existing programs such as the National Immunization Program. But given that their hands have been figuratively tied because of an inability to fund what they know to be the necessary components of an effective hepatitis C prevention and control program, they have resorted to the only avenue left open to them. They have tried to establish a network to begin coordinated efforts at the state level by establishing the

Hepatitis C Coordinators program. However, limited funds cover the salaries for these positions without providing any funding for these professionals to actually conduct hepatitis C prevention and control activities. So their hands, too, have been tied. Thirty-three states currently have hepatitis C prevention and control plans prepared and ready for execution – but have been unable to act upon those plans due to lack of funds. Similarly, SAMSHA is ready and willing to take part in hepatitis C prevention and control efforts, but have been unable to act because of the absence of a directive to spend funds on such activities.

Hepatitis C national advocacy and community-based organizations have put forth heroic efforts to try to provide much-needed prevention and control services. Funded virtually exclusively by private fund-raising and small non-federal grants, the organizations of the National Hepatitis C Advocacy Council have:

- conducted local screening, counseling, and testing programs
- worked with corrections facilities to improve hepatitis C efforts for the incarcerated population
- collaborated with harm reduction programs to provide hepatitis C education to at-risk populations
- authored a comprehensive, patient-oriented book about hepatitis C
- countless other daily efforts by a legion of unsung heroes

We are doing the best we can on what amounts to a wing and a prayer, and a passionate commitment to those afflicted with this disease. But we are sadly aware that our efforts are barely scratching the surface of what needs to be done to address this crisis. We – the DHHS agencies, the state and local health departments, and the hepatitis C advocacy organizations – must have funding to do the work we know must be done and that we are fully prepared to do.

IV. SUMMARY

Former Surgeon General Dr. C. Everett Koop summarized the current status of the hepatitis C crisis by saying: *We are at the edge of a very significant public health challenge - not unlike the AIDS epidemic. We have an infectious disease that is an undisputed threat to the public health. It is a viral disease that millions of people harbor without knowing they have it. It is a disease these millions will carry for a decade or more - possibly spreading to others - while it develops into a serious threat to their health. We can treat the disease during this quiescent period and we can eliminate the infection for a large portion of the infected, preventing progression to serious disease…. we have a long way to go very quickly if we are to prevent the very serious public health consequences of this disease.*

Hepatitis C is **everyone's disease**. Many of the millions of Americans infected with HCV are average citizens just like you, me, our family members, and friends:

- middle-aged working class men and women who may have had a blood transfusion due to surgery, injury, or childbirth
- young adults who had transfusions as premature babies
- military veterans of Vietnam, Desert Storm, and the young men and women coming home from Afghanistan and Iraq

- hard-working, productive men and women who experimented briefly with drugs in the folly of their youth

Unlike most viral diseases from the common cold to influenza to AIDS, HCV is a treatable illness. In other words, unlike many other afflictions, we have the opportunity to intervene in this crisis with the potential to achieve a viral cure in approximately half of those treated. We have a rare opportunity with HCV; we must not squander it.

We are at a critical juncture. We are faced with an awakened giant, the hepatitis C crisis. Ignoring this giant will lead to dire personal, societal, and fiscal consequences. Opting to fund a comprehensive hepatitis C prevention and control program now will save hundreds of thousands of lives, millions of years of pain and suffering, and billions of dollars in direct and indirect costs.

Again, hepatitis C is **everyone's disease**. Dr. Koop's message is clear: *Hepatitis C does not discriminate. It affects people of all ages, gender, and sexual orientations. It is not a "disease of the poor." It affects people from all walks of life, in every state, in every country. Most important, it affects a large number of individuals, a group in the United States that is as large as the populations of every capital city, in every state combined. All Americans must understand the risk that this disease poses. We must help America become a leader in the fight against this disease, both here at home and around the world.*[16]

I am one of the many faces of hepatitis C, and I stand before you today as one of the lucky ones. Not only am I a treatment "veteran," but also a successful responder to treatment for this insidious disease. Unlike so many unsuspecting people infected with hepatitis C, I was fortunate enough to get tested. And unlike many people currently struggling with hepatitis C, I had adequate insurance coverage and was thus able to afford treatment. Above all, I was fortunate to have successfully cleared the virus. I remain virus-free more than six years later.

In gratitude for my good fortune, the misfortune of the millions of others infected with hepatitis C, not to mention more than two million Americans who are not aware they are infected, is never far from my mind. I cannot forget about them, and neither should you. Just as I pled for attention before this same Congressional Committee in March of 1998, I repeat my plea with even greater passion today.

We have a moral, professional, and fiscal responsibility to the American people to act **now** to implement a federally-funded, comprehensive hepatitis C prevention and control program. It is not only our responsibility, it is the only humane option possible.

Thank you for your time and attention.

APPENDIX: FIGURES 1-4

Figure 1:

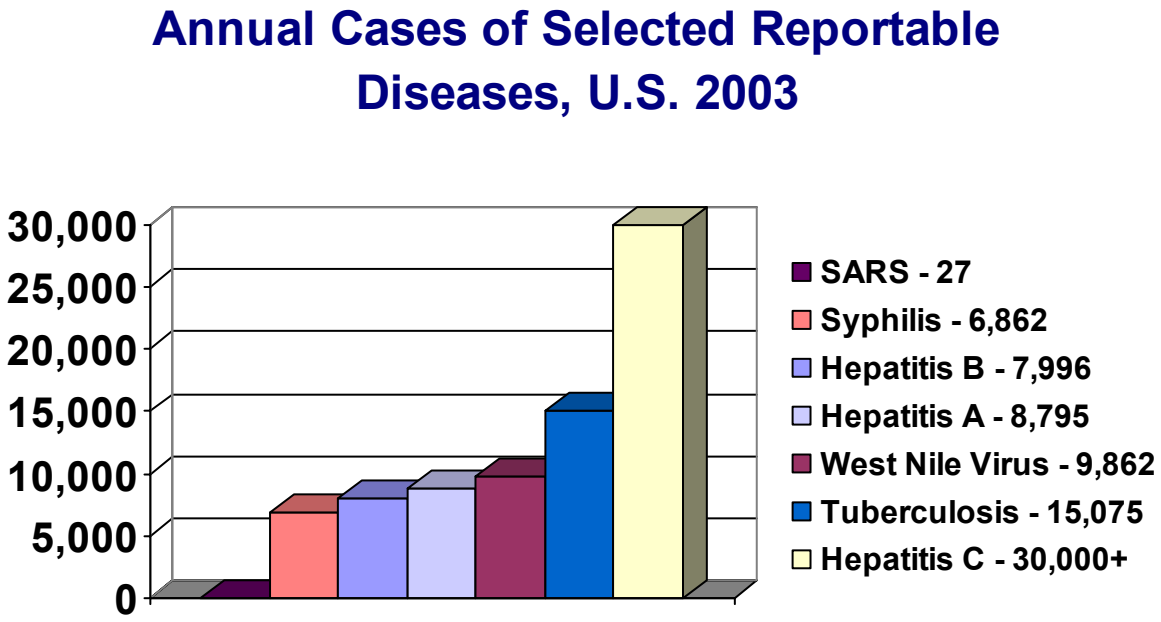


Figure 2: Projected HCV-Related Morbidity, Mortality, and Costs in the United States, 2010-2019[15]

HUMAN COSTS	
Deaths from HCV-related chronic liver disease	165,900
Deaths from hepatocellular carcinoma	27,200
Years of advanced liver disease	960,000
Years of life lost	3.1 million
SOCIETAL & FISCAL COSTS	
Direct medical costs	$10.3 billion
Cost of lost productivity due to disability	$21.3 billion
Cost of lost productivity due to premature death	$54.2 billion

Figure 3

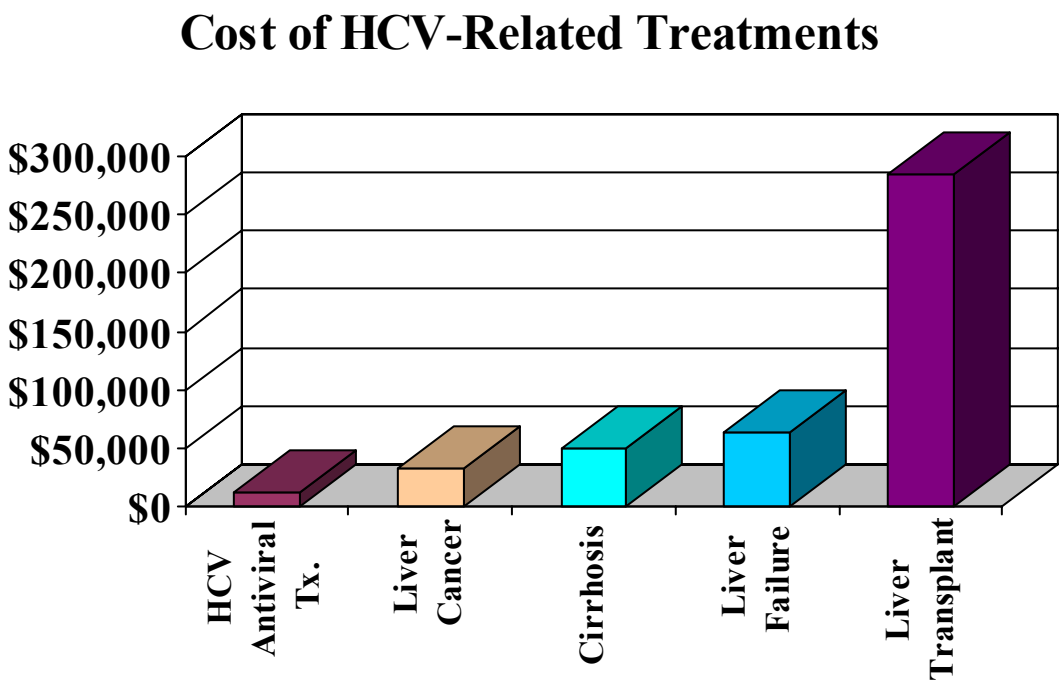
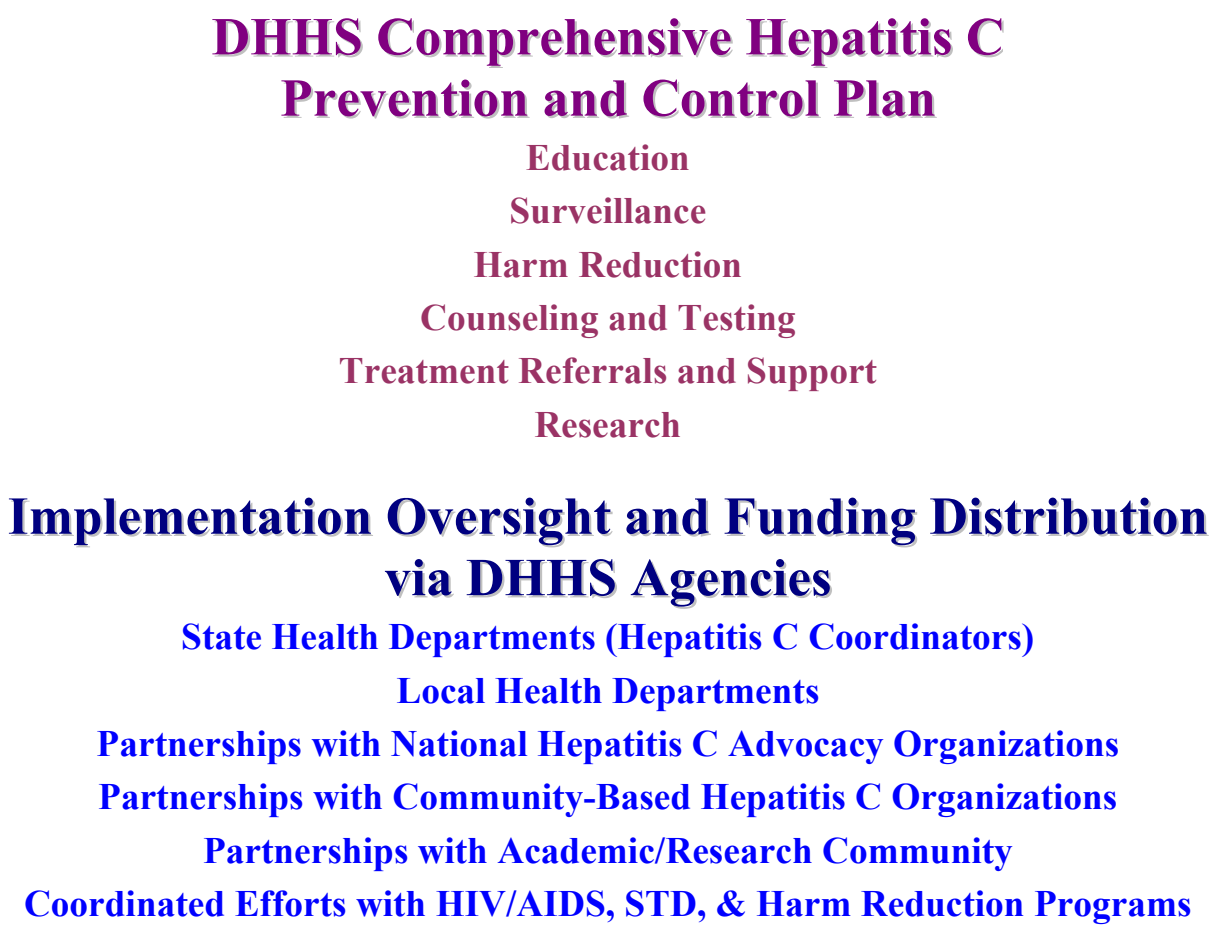

Cost of HCV-Related Treatments
$300,000
$250,000
$200,000
$150,000
$100,000
$50,000
$0
HCV Antiviral Tx.
Liver Cancer
Cirrhosis
Liver Failure
Liver Transplant

Figure 4: Hepatitis C Prevention and Control Program Model



References

[1] www.epidemic.org
[2] Alter MJ. Hepatitis C: a sleeping giant? *Am J Med*. 1991;91(3B):112S-115S.
[3] World Health Organization. Summary of probable SARS cases with onset of illness from 1 November 2002 to 31 July 2003. www.who.int/csr/sars/country/table2004_04_21/en.
[4] Centers for Disease Control and Prevention. Summary of Notifiable Diseases – United States, 2002. *MMWR*. 2004;51(53):1-84.
[5] *Ibid*.
[6] Centers for Disease Control and Prevention. 2003 West Nile Virus Activity in the United States. www.cdc.gov/ncidod/dvbid/westnile/surv&controlCaseCount03_detailed.htm.
[7] *Ibid*, ref 4.
[8] Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2003 (Vol 15).
[9] Kingsley LA, Detels R, Kaslow R, et al. Risk factors for seroconversion to human immunodeficiency virus among male homosexuals. results from the Multicenter AIDS Cohort Study. *Lancet*. 1987;1:345-9.
[10] Landesman SH, Kalish LA, Burns DN, et al. Obstetrical factors and the transmission of HIV type 1 from mother to child. *N Engl J Med*. 1996;334:1617-23.
[11] Zanetti AR, Tanzi E, Paccagnini S, et al. Mother to infant transmission of hepatitis C virus. *Lancet*. 1995;345:289-91.
[12] Thomas DL, Villano SA, Riester KA, et al. Perinatal transmission of hepatitis C virus from HIV type 1 infected mothers. *J Infect Dis*. 1998;177:1480-8.
[13] Eyster ME, Alter HJ, Aledort LM, Quan S, Hatzakis A, Goedert JJ. Heterosexual co-transmission of hepatitis C virus and human immunodeficiency virus. *Ann Intern Med*. 1991;115:764-8.
[14] Verucchi G, Calza L, Manfredi R, Chiodo F. Human immunodeficiency virus and hepatitis C virus coinfection: epidemiology, natural history, therapeutic options and clinical management. *Infection*. 2004;32(1):33-46.
[15] Wong JB, McQuillan GM, McHutchison JG, Poynard T. Estimating future hepatitis C morbidity, mortality, and costs in the United States. *Am J Public Health*. 2000;90(10):1562-9.
[16] Hepatitis C: An Epidemic for Anyone. www.epidemic.org/textMessage.html. Accessed 12/09/04.